

# Research Case Study: Partnering with Health Consumers In Analysis of Research To Improve Hospital Test Result Management – Part 2: Maureen – A participant in the workshop

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## Upcoming Events

**What Involving People in Research Can Look Like – Sydney 11Dec19**  
(<https://research4.me/partnering-with-health-consumers-in-analysis-of-research-workshop-part2/#comments>)

December 11 @ 10:25 am - 1:30

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We recently shared in Part 1 of this story insights from Dr Mary Dahm (<https://research4.me/partnering-with-health-consumers-in-analysis-of-research-workshop-part1/>) about a workshop she held to gather health consumer input in her research analysis. We thought it would be valuable to also hear from a couple of the consumers that attended about their experience at the workshop and why they are interested in being involved in research. Maureen, pictured above, was one of those that participated and she kindly offered to share her experience with us.

***When did you first get involved as a health consumer representative?***

I have lived with Addisons Disease for over 40 years. It is an extremely rare autoimmune condition which is potentially life threatening. After some bad experiences I educated myself and this led to my becoming a patient advocate.

About 10 years ago, through common connections, I was invited to be part of the inaugural committee for the Institute of Patient and Family Centred Care. Out of that, I morphed into almost a full-time patient advocate. As examples, I've worked with Monash University, and the College of Emergency Medicine. At the moment I am doing a Master's of Public Health to improve my knowledge of the health system.

***How did you become aware of Mary's research project and workshop?***

I've been interested in diagnostic error as Addisons Disease is often undiagnosed, which can have fatal consequences, as a coroner's inquest into the death of two young people with undiagnosed Addison's Disease found. Mary is on the organising committee for the next international conference on diagnostic error, which we're organizing in Melbourne next April, and we were on the organizing committee for last year's conference together, and so I see her from time to time at committees meetings. That's how I met Mary and got interested in and involved with her particular research. Mary mentioned that she was doing the workshop. I said to her that if she felt I had anything to contribute to ask me, so she did.

***What were your expectations going into the day?***

Look, I really didn't know. I've been involved in an enormous amount of advocacy and committee meetings, but I've not done research before so I didn't have any expectations. I found the day, really interesting and informative.

There were interesting questions, but for me personally, every time we talked about any of the subjects, in my mind was the word communication. There was discussion about how some patients want information and some don't. And to me, the answer is screaming out, "Just ask them."

***What was good about the workshop and what was done in the leadup to it?***

I thought Maria was incredibly professional. She gave us a lot of information to read up before we actually came and asked us in the weeks leading up to it what we felt were the most important aspects of testing to be considered. I put communication first but that obviously wasn't the most popular. The group came up with two main questions, and then had the opportunity to consider the responses collected from interviews with patients, clinicians, and pathologists, and make comments about them.

We had a lot of pre-reading to do. A few people at my table hadn't read the material in advance. So, when the research came up and we were asked to write down what we thought about it, there were a few people around the table that had to read through it before they could do that. But, the organisation was great.

***Did you feel that you had enough time to do that work in advance?***

Absolutely, yes.

***How was communication on the day, and since the workshop?***

Information was well communicated, and it was a really great way to get input on the day. There were five tables and we had white paper in the middle of the table and we were asked to discuss each question as a group and write down the points that we thought were important. One person on each table was allocated to speak on our behalf. I thought it was a really good way to do it. And it was very interesting because the points your group raised

were sometimes different to those raised by other tables... there would be one or two ideas that you hadn't even thought of, which was really good.

***It just***



***demonstrates the impact of the experience on how people look at a question.***

Yes, we all look at life from our own life's experience and our own history and our own world view. And so, it's always interesting when you get a group of people sharing like that.

***How did you find communication with the researchers. Was that easy, or was the language an issue?***

The research professionals at our table were very good at convening, and one was well experienced talking with consumers, so I didn't strike any communication issues.

***Given you have vast experience as a patient and having been on committees, what do you think helped you to be able to contribute on the day?***

I felt that I had quite a lot to contribute really, because of my experience and particularly at emergency department level where the first thing they do is take tests.

***So, do you think because you do have a strong educational history as well that it makes a difference to your ability to contribute?***

Yes. I think it does. I started life an opera singer and this has given me the confidence to speak at medical conferences. A lot of patient advocates find it difficult to speak in public, but fortunately, it doesn't bother me.

Then, there is the 40 years experience of my journey through Addison's Disease and my degree and counselling and communication. And I'm now doing the Master's of public health and finding a huge connection between my degrees. Being happy, and healthy are only a very small proportion of the equation. Most of the rest of it is psychological and social aspects, and what sort of background you come from.

To answer your question, yes, I think that having a background in something other than just your health experience is very useful.

***Do you think there are any other skills that are important to be able to contribute effectively as a health consumer?***

A holistic approach and understanding that, okay, so, you're dealing with a specific illness, but other people have got something else which has a different set of symptoms and a different set of treatments and a different need to deal with it.

You also need to have an interest in health.

I think public speaking is important. In this day of technology where everybody tweets and sends messages on their phones and nobody is actually talking, it's so important to learn how to speak. If you want to get a message across, you need to be able to deliver it in a way that people will listen. It's something I grapple with personally and have to push myself out there to do. And so, I never feel completely comfortable in it. So, sometimes it works and sometimes it doesn't.

There are still a number of doctors who are very anti-patient advocates. They think we're interfering. So you have to be able to communicate effectively and respectfully to be accepted.

***Would you do something like Mary's workshop again?***

Yes, sure. And I've offered to continue involvement if they feel I've got anything to contribute.

***Why do you think consumers should be involved in research?***

I always say at my talks, and this has become a bit of a catchphrase for me, but as patients, we're absolutely in awe of everything that doctors know. Their level of knowledge is phenomenal. But at the same time, they spend a matter of hours with us, whereas, we've lived in our bodies for 24/7, for as many years as we've been on the planet. We're the experts on us, we just need to be asked.

***Did you ever have any formal training around being a consumer rep in health or research?***

When I decided a couple of years ago I'd like to do more study, I went looking for patient advocate training (I don't like the word consumer) and the only one I could find was in America. So, I don't think that there is very much. The Cancer Council do some consumer training which is extremely useful, but when it's one day or it's a specific illness, the focus is too narrow.

I really think there is a need for patient advocates to be trained in a holistic way. They can then contribute to changing policies and strategies at government and organisational level. This can improve the level of health for all.

***Any advice would you give to people thinking about working with researchers?***

I don't know that that's something that you can give people advice about. It depends on their level of health literacy, really, doesn't it?



But, I think if a patient is interested in their condition, and interested in helping to improve it, then being in research is a really fabulous way to do it. It gives you a feeling of that you're contributing. Your experience may in fact help other people. And I think that if you've got the time and the inclination, it's something that I would encourage people to get involved in.

Thanks to Maureen for sharing your experience with us, and to Dr Mary Dahm (<https://twitter.com/drmmarydahm>) for sharing photos from the day including Maureen.

For anyone interested in getting more involved in research, our Research Gamechangers Facebook Group (<https://www.facebook.com/groups/Research4MeGameChangers/>) is a place you are welcome to ask questions and tap into the experience of other members, or share your own experiences. You can also sign up for our newsletter (<https://research4.me/newsletter/>), register on our volunteers database ([https://research4.me/volunteer\\_for\\_medical\\_research/](https://research4.me/volunteer_for_medical_research/)), or just pick up the phone (<https://research4.me/contact/>) and talk to us about your interests.

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